



**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – December 12, 2011 (ratified)
6pm – 9pm
NJ Department of Health and Senior Services, Health & Agriculture Building
369 South Warren Street, Trenton, NJ 08625-0360**

Council Members Present

Elizabeth K. Bell, BS, volunteer and independent contractor with Autism Speaks,
Autism Organization Representative

Matthew Cortland, BA, Instructor, Teach for America, Public Member

B. Madeleine Goldfarb, MA, Founder/Director of the Noah's Ark Children's Association,
Autism Organization Representative

Ketan Kansagra, MD, FAAP, Children's Hospital of New Jersey at Newark Beth Israel Medical
Center, Academic Institution Representative

Linda S. Meyer, EdD, MPA, BCBA-D Executive Director of Autism New Jersey, Autism
Organization Representative

Barbara Morvay, MA, Trustee, Richard Stockton College of New Jersey, Academic Institution
Representative

Grace M. Reilly, RN, MSN, APN-C, Adult Nurse Practitioner for Riverview Medical Center,
Individual with Autism or Family Member Representative

Gary Weitzen, BA, Executive Director, Parents of Autistic Children (POAC) Autism Services,
Organization Representative

Absent

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,
Healthcare Organization Representative and Chair of Governor's Council for Medical Research
and Treatment of Autism

Susan P. Evans, EdD, Education Program Specialist for Early Intervention Program,
Commissioner of Health and Senior Services Appointee

Judah Zeigler, Senate President Appointee

NJ Department of Health and Senior Services (DHSS) Attendees

Martin T. Zanna MD, MPH
Acting Executive Director
Governor's Council for Medical Research and Treatment of Autism

Cynthia Kirchner, MPH
Director, Quality Improvement
Ethics Liaison for the DHSS

Linda N. Bocclair, M.Ed., MBA
Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research
Commission on Spinal Cord Research

General Public Attendees

Audrey Mars, MD
Medical Director, Regional Autism Center at Hunterdon Medical Center

Yvette Janvier, MD
Medical Director, Children's Specialized Hospital

Jill Harris, Ph.D.
Autism Program Director, Children's Specialized Hospital

Pnina Mintz, Ph.D.
Center for Neurological and Neurodevelopmental Health (CNNH)

Mark Mintz, MD
Center for Neurological and Neurodevelopmental Health (CNNH)

Jonathan Sabin
Director, Office on Autism, Dept. of Human Services

I. Welcome - Council Chair, Dr. Linda Meyer called the meeting to order at 6:10 PM and welcomed everyone.

II. Public Meetings Act Announcement- Dr. Meyer read the Public Meetings Act, followed by roll call.

Comments by Ms. Cynthia Kirchner, Director of Quality Improvement and Ethics Liaison.

Ms. Kirchner thanked everyone on Council for their leadership and for the significant progress made during the year including the efforts of everyone to understand and adopt the Code of Ethics. The work of the Council is also acknowledged in a Press Release dated December 5, 2011 highlighting the release of \$8M in grants to fund the New Jersey Autism Center of Excellence (NJ ACE) Coordinating Center and Program Sites. Ms. Kirchner thanked the Council's staff for their exceptional work throughout the year in organizing Council meetings, writing reports, monitoring grants, participating in autism related events, working with consultant Dr. Daphne Robinson and several Council members in developing and reviewing the NJ ACE grants and ongoing correspondence with grantees and other stakeholders.

Dr. Meyer thanked Ms. Kirchner and her team for their hard work and accomplishments over the past year – “much appreciated” said Dr. Meyer.

III. Approval of the September 12, 2011 Council Meeting Minutes and approval of an additional Council meeting in 2012

Dr. Meyer called for a motion to approve the minutes. MOTION by Ms. Goldfarb to approve the minutes was seconded by Ms. Reilly.

MOTION to approve the minutes was passed with all in favor.

Dr. Meyer called for a motion to approve the addition of a Council meeting on Monday May 21, 2012 to enable Council to vote to approve funding for the NJ ACE Coordinating Center and Program Sites. MOTION by Mr. Weitzen to approve the May 21, 2012 meeting was seconded by Ms. Goldfarb. As a result of the additional meeting, Council will meet five times in 2012.

MOTION to approve the addition of the May 21, 2012 Council meeting passed with all in favor.

IV. Membership on Council and Notice of Grant Availability as related to the Council's Code of Ethics

Ms. Kirchner noted that at the time the agenda was prepared there was the potential for conflict of interest with Council members related to the availability of funding by the Council for the NJ ACE. Ms. Kirchner noted that at this point no Council member is conflicted.

Grant Timeframe

Ms. Kirchner explained the grant timeframe to ensure that Council understands the process following the Notices of Grant Availability (NOGA). The NOGAs (one for the Coordinating

Center and one for the Program Sites) were published in the December 5, 2011 issue of the New Jersey Register. Letters of Intent are due to the Council staff by February 17, 2012. While the letters are not required, applicants are encouraged to submit letters to enable the Council staff to prepare for the grant review process.

The application due date is March 19, 2012 followed by a very rigorous review including an internal relevancy review. Applications must be in accord with the Clinical Research Program Guidelines with all components included and no conflicts of interest with Council members. Applications that pass the relevancy review are sent to the scientific external peer review panel. Drs. Zanna and Robinson will work with Ms. Kirchner and the Council's staff to select panel members who, in turn, will analyze and score the grant applications based on the evaluation criteria included in the Clinical Research Program Guidelines. Once the applications are scored those that score above the cutoff (as determined by the external peer review panel) will be available on line to Council a minimum of 10 days prior to the May 21, 2012 Council meeting, along with the scoreboards and blinded reviews from the reviewers.

At the May 21, 2012 meeting Council will vote to approve funding for one Coordinating Center and up to three Program Sites. DHSS will then issue notices of grant awards by June 1, 2012 with anticipated start dates of June 15, 2012. Ms. Kirchner will check with legal counsel in regards to the public meeting law to ascertain if the May 21 meeting can be conducted as a closed meeting session to address the grant applications.

Status of Vacancies on the Council

With respect to the vacancies on the Council, Ms. Kirchner reported that notice of Dr. Kendall Sprott's resignation, effective December 5, 2011, has been sent to the Governor's appointment office and notice of Dr. Barbie Zimmerman-Bier's resignation, effective December 12, 2012, will be sent shortly. Ms. Kirchner noted that, since both resignations were from physicians, a recommendation will be made to the Governor's appointment office to give priority to clinical physicians with expertise similar to that of Dr. Zimmerman-Bier and Dr. Sprott when appointing members to the Council.

Ms. Kirchner responded to a request for clarification of the attendance policy as related to members who have missed an excessive number of Council meetings. The Council staff is working with the Governor's Appointment Office and requesting the Office to accept a recommendation to remove a member from Council if that person attends less than 50% of Council meetings, without strong justification, within a calendar year.

V. FY13 budget discussion- Grants to fund in FY 13

Ms. Mary Ray recommended that Council consider the availability of funding for basic science grants in FY 13 (July 1, 2012 – June 30, 2013). Council has obligated \$8M for the new clinical research grants for the next five years with an estimated fund balance of \$2.3M to \$2.4M to be carried over into FY 13. It is recommended that Council offer \$2M to fund basic science research grants in FY 13 due to the need to set aside funds each year over the next five years to fund the next cycle of clinical research grants. The projected \$2.3M to \$2.4M fund balance in FY

12 will partially fund FY 13 basic science grants along with revenue during the beginning of FY 13. Ms. Kirchner noted that in addition to funding the clinical research and basic science grants, Council sets funds aside to fund the Autism Registry and office expenses. The plan is to enable Council to continue to fund the basic science grants on an annual basis while preparing for the second cycle of clinical research grants in FY 17.

Revenue has been consistent over the past few years at \$3.5M to \$4.0M annually. Ms. Kirchner explained that for every moving vehicle violation there is a \$1.00 surcharge collected by the municipalities and sent to the state treasury on a monthly basis. The funds are sent from the state treasury to the Council through the DHSS and deposited in the Autism Medical Research and Treatment Fund. The funds accrue interest and Ms. Ray receives monthly statements of revenue.

The question was asked if the \$2M could be used for research other than basic science such as supplementing the clinical research program. At one time Council considered funding applied research and members served on a sub-committee to discuss the possibility of funding applied research focused on behavioral interventions. Also, a comment was made that the needs assessment being conducted by Rutgers can and should inform the decision-making process, considering the need for research in other areas such as transitions and support systems. The question was asked if a decision of the type of research could be made at a later date. Ms. Ray commented that the notice of grant availability can be written for research grants with several types listed and the grantees would select one of the categories of available grants. The research grants must adhere to the language of the Statute. It may be beneficial, considering national initiatives, to have the flexibility in funding the specific type of grant annually with the \$2M.

Ms. Kirchner commented that the former DHSS Commissioner had proposed funding fellowships to encourage researchers to come to NJ to address autism issues from a clinical perspective. Ms. Kirchner requested that Council consider the option of funding fellowships. She will provide information that addresses the requirements and options for the levels of funding.

Dr. Meyer called for a motion. MOTION to fund \$2M for autism research in FY 13 by Ms. Goldfarb was seconded by Dr. Kansagra.

MOTION to fund \$2M for autism research in FY 13 was passed with all in favor.

Ms. Kirchner commented that Ms. Bocclair will send what has been proposed including the parameters of the Statute and ask for interested members to sign up for a sub-committee to discuss the issues raised by Council.

VI. Report of the Acting Executive Director, Martin T. Zanna, MD, MPH

Autism New Jersey 29th Annual Conference – October 13-14, 2011

Thanks to Dr. Linda Meyer, the basic science research and Clinical Enhancement Center grantees were invited to participate in the poster session event on October 13 at Autism New Jersey's 29th Annual Conference in Atlantic City. The session was a tremendous

success in highlighting the contributions of the Council in supporting autism research and clinical services statewide.

And special thanks to the nine grantees presenting a total of 16 posters. They are Dr. Randy Huron (Hackensack University Medical Center), Dr. Mark Mintz (Center for Neurological and Neurodevelopmental Health (CNNH)), Dr. Denise Aloisio (Jersey Shore University Medical Center), Dr. Audrey Mars (Hunterdon Medical Center), Dr. Gleb Shumyatsky (Rutgers), Dr. Walter Zahorodny (UMDNJ), Drs. Yvette Janvier and Jill Harris (Children's Specialized Hospital), Drs. Diccio-Bloom and Matthieu Genestine (UMDNJ) and Drs. Dennis Carmody & Michael Lewis (Rutgers).

Administrative Issues and Website

As noted by Ms. Kirchner, Dr. Kendall Sprott resigned from Council effective December 5, 2011. Dr. Zanna thanked Dr. Sprott, on behalf of the Council, for his years of participating on the Council acknowledging that his leadership and expertise in the field of pediatrics as well as special interest in autism has been a valuable resource in advancing the work of the Council.

Dr. Zanna will also formally thank Dr. Barbie Zimmerman-Bier, who submitted her resignation today, for her contributions to the Council.

Website postings since the last Council meeting include the Year 3 Summary Reports from the Clinical Enhancement Centers and the NJ ACE grant application information.

Grant Monitoring – Quarterly and Year 3 Summary Reports

First quarter FY12 Quarterly progress reports are being reviewed. Jersey Shore University Medical Center completed all grant requirements effective October 31, 2011 leaving UMDNJ, Hunterdon Medical Center and Hackensack University Medical Center active through no cost extensions. Site visits will be scheduled, on a selective basis, beginning in January.

Responses to Council's requests re: basic science research grantees Progress Reports

All four basic science research grantees complied with Council's requests for additional information in reference to their first year progress reports. The information submitted by the grantees was reviewed by both grant reviewers and Dr. Zanna and found to be acceptable. Dr. Zanna plans to visit two of the grantees in January.

Scientific Advisory Committee (SAC)

Dr. Zanna noted that five SAC members (two clinicians and three researchers) have been confirmed. SAC membership is in compliance with the Statute (P.L. 2007 c. 168). Outreach to potential members was based on two factors: (1) Recommendations from Dr. Alice Kau who oversees the NIH funded Autism Centers of Excellence and (2) Previous priority rankings by Council members.

The five individuals who have agreed to serve: Catherine Rice, Ph.D., CDC (and affiliated with the Marcus Autism Center at Emory). Dr. Rice is a member of the CDC's Autism Surveillance/monitoring Unit (ADDM); Ted Abel, Ph.D., Director of the Biological Basis of Behavior Program at the University of Pennsylvania; Susan Hyman, MD (University of Rochester and Chair of the Autism sub-committee of the American Academy of Pediatrics, Stewart Mostofsky MD, Medical Director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute; and Joseph Buxbaum Ph.D. Professor of Genetics and Genomic Sciences at The Mt. Sinai Medical Center. Three of the individuals (Drs. Rice, Hyman and Abel) also serve on national autism related scientific advisory boards. In addition, Dr. Zanna has dialogued with Dr. Kim Van Narden-Braun. She is a member of Dr. Rice's team at CDC and is currently embedded in the DHSS Family Health Services. She is poised as part of Dr. Rice's team to provide assistance.

March 2012 Scientific Meeting of the Council funded Research Grantees

Plans for the full day scientific meeting of Council funded research grantees scheduled for Friday March 23, 2012 are being finalized. This is a new initiative by the Council and the start of what we hope to ultimately be a statewide program to bring all autism researchers together annually for a summit to present and hear about the "State of the State of Autism Research in New Jersey". Twenty of the twenty-nine researchers who were contacted plan to attend the meeting.

Following Dr. Zanna's comments, Council discussed the plans for the meeting. Ms. Goldfarb explained that the intent of the meeting is to provide opportunities for future collaboration among the researchers and to learn about the research projects including highlights, publications, additional funding and the impact of Council funding. The agenda will also include topics of interest as expressed by the researchers in surveys that they have returned to Council's staff.

Council agreed that the meeting should be open to the public and notices should be posted as they are for the Council meetings. As a result of the budgetary restrictions, space will be limited with a maximum 40 participants including the researchers, Council members and staff and public members. Researchers will be notified that the meeting will be open to the public. Ms. Kirchner responded to questions regarding increasing the budget, recording the meeting and charging registration fees. While the meeting is a priority for Council Ms. Kirchner explained that requesting additional funds at a time when the state is closely monitoring all expenses will jeopardize approval of the submitted request for funds. In reference to registration fees, the Council does not have a mechanism for participants to pay and time is too short to consider establishing one.

Interagency Task Force on Autism

The focus of this group, with representatives from the Department of Human Services, Department of Health and Senior Services, Department of Education, Department of Children and Families, Department of Community Affairs, Department of Labor and Work Force Development, Department of Law and Public Safety, the Boggs Center on Developmental Disabilities and the Governor's office, is on professional education. All members reported on

activities statewide. Dr. Zanna summarized the autism training and education presented by the Clinical Enhancement Centers to healthcare professionals and was impressed with the amount of training provided over the past three years. A draft of the final report is now under internal review.

Note: The following three PowerPoint presentations summarized below will be posted at www.nj.gov/health/autism “Reports/News/Meeting Minutes”.

VII. Children’s Specialized Hospital (CSH) Clinical Enhancement Center Presentation by Dr. Yvette Janvier, Medical Director

Dr. Janvier provided an overview of achievements throughout the three years (July 1, 2009-June 30, 2011) of Council’s funding for CSH’s Clinical Enhancement Center. The primary objectives were to expand services and provide early identification of children with ASD and quality assessment & intervention as quickly as possible following referral. Dr. Janvier’s presentation was followed by a Q&A session. Her slide set was made available to Council members. Dr. Meyer, on behalf of the Council, thanked Dr. Janvier for a most informative presentation reflecting CSH’s accomplishments in enhancing services for individuals with autism.

VIII. Rutgers Center for State Health Policy Needs Assessment Presentation by Dr. Dorothy Gaboda, Associate Director for Data Analysis

Dr. Gaboda discussed Phase 1 of the Needs Assessment Report that had been sent to the Council for review. The final report is due in February 2012 and will inform Council about the status of clinical and basic science research and services for individuals with autism, highlighting the needs and gaps in research and services. The report can be used by Council in guiding their strategic planning. During Phase 1 Dr. Gaboda and her team gathered and reviewed background information including previous New Jersey reports and national priorities for autism-related biomedical research and then cataloged autism-related funded research in New Jersey. She reported that over 80 research grants were awarded to NJ researchers between 2005 and 2010 with total ASD-related research funding over \$103 million. Funders included the National Institutes of Health (NIMH, NICHD, NINDS, NIEHS, NIA, etc.), Autism Speaks, Simons Foundation, National Center for Birth Defects and Developmental Disabilities, Autism Research Institute, ASPEN, Governor’s Council and pharmaceutical companies.

Dr. Gaboda also reviewed funding priorities of the Interagency Autism Coordinating Council (IACC) and Autism Speaks to give sense of the national agenda. While New Jersey has lagged behind other states in acquiring federal funding there is a significant amount of autism research being conducted in New Jersey with some researcher’s spring boarding Council funding into federal grant awards. It has been thought that the reason for New Jersey lagging behind may be that there is not an optimal infrastructure in the state to support NIH level research.

Dr. Gaboda also noted that some Council funding may not have been linked to federal initiatives. While the funded research was good it was not federally qualified (aligned with federal priorities for funding) and thus did not lead to new federal research dollars. Ms. Kirchner commented that the new RFAs were designed to align research in New Jersey to the federal priorities with the intent of preparing more researchers to compete for federal funding.

New Jersey has an opportunity to build on autism research currently funded since there are already several high-profile nationally recognized researchers in the state. Another strength in New Jersey's ability to acquire additional federal funding is that funding has been awarded to several New Jersey organizations by NIH, NIMH and Autism Speaks for mentored research.

Dr. Gaboda and her team are in the process of completing interviews with researchers, clinicians, family members, service providers, advocates and educators for the Phase 2 Report with a draft of the report due the end of December. The final report is due in February 2012.

Dr. Meyer, on behalf of the Council, thanked Dr. Gaboda for a very interesting and informative report.

IX. Statewide Parent Advocacy Network (SPAN) Presentation on the NJ State Implementation Grant – Year 1 by Diana Autin, Executive Director

Ms. Autin provided an overview of the NJ State Implementation Grant highlighting the partnerships and collaboration among stakeholders statewide. Significant progress has been made during the first year of the grant. The goals of the grant are to: (1) establish the leadership & structure needed for an integrated system of services for CYSHCN-ASD/DD; (2) improve access to care through medical homes; early & continuous screening to identify ASD/DD; community-based services; and adequate health insurance & financing; (3) increase focus on unique needs of YSHCN-ASD/DD in transition & youth self-advocacy and (4) improve participation of families in all aspects of individual child's care & systems improvement.

Ms. Autin described each component of the grant and discussed the following outcomes: (1) family-professional partnerships & satisfaction with services; (2) ongoing, coordinated care within a medical home; (3) adequate insurance to pay for needed services; (4) early & continuous screening to identify special health care needs; (4) community-based services organized for easy use and; (5) effective transition to adult systems of care & services.

Dr. Meyer, on behalf of the Council, thanked Ms. Autin for a very interesting and informative report.

X. Report of Revenue and Expenditures

Ms. Ray presented the Revenue and Expenditures Report (July 1, 2011 – June 30, 2012). There were no comments or questions.

XI. Comments by public member attendees

Dr. Audrey Mars commented on behalf of herself and some of the other clinical enhancement centers that not all centers will be applying for the new grants. She asked that Council consider including sites that have been previously funded in some way as well as other sites that provide excellent clinical care. She would like to see a way that those patients who get excellent care can be part of clinical research programs. Dr. Mars commented that clinicians want to diagnose as

soon as possible and that there will always be a balancing act between research and clinical care. She asked Council to consider the importance of clinical care/enhancement in addition to research. How can clinical sites that will not be funded be part of this project?

XII. Adjournment

MOTION by Ms. Bell to adjourn the meeting and seconded by Ms. Goldfarb.

MOTION passed with all in favor. The meeting was adjourned at 9:00 PM.